DOCUMENT RESUME

ED 242 124 EC 161 894

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TITLE [Community-Based Management for Persons with Handicapping Conditions: A Comprehensive Service Model.]
PUB DATE Nov 83
NOTE 40p.; Paper presented at the Annual Conference of the Association for the Severely Handicapped (10th, San Francisco, CA, November 3-5, 1983).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Adaptive Behavior (of Disabled); Adjustment (to Environment); *Behavior Modification; Behavior Problems; Community Resources; *Deinstitutionalization (of Disabled); *Disabilities
IDENTIFIERS *Ontario

ABSTRACT

York Behaviour Management Services, one of 33 programs funded by the Ontario (Canada) Ministry of Community and Social Services, is designed to help deinstitutionalized handicapped persons adapt to the demands of community life. An introduction (presented by D. Griffiths) on the background of behavior modification reviews reasons for some negative attitudes toward the approach. The management system advocated in the paper differs from some previous applications in that service is provided in the client's normal environment, and help is also provided to critical support persons in the environment. Further discussion of the model centers on its application to transitional planning for deinstitutionalization (presented by Linda Hickey); services (focusing on prevention) offered to parents, teachers, direct care staff and other mediators in the community (presented by Lynann Outram); and a preventive orientation to serious behavior problems (presented by Andrew J. R. Harris). (CL)

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[Community-Based Management for Persons with Handicapping Conditions

A Comprehensive Service Model]

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Paper Presented

at

The Association for the Severely Handicapped

Annual Conference

10th

San Francisco, California

November 1983

PRESENTATION: Community-Based Behaviour Management
The Association for the Severely Handicapped
San Francisco 1983

Introduction: D. Griffiths

York Behaviour Management Services is one of thirty-three such programmes funded by the Ontario Ministry of Community and Social Services. The programme is funded to provide support for persons with handicapping conditions so that they are able to adapt to the demands of integrated, community living.

It has been the policy of our government since 1973 to:

(i) retain, where possible, the person with handicaps with their family, and

(ii) to provide community-based support, residential and service programmes to meet this end.

As a result, a greater number of individuals with handicapping conditions are remaining in the community and returning from facilities. Our province is presently in a 5 year process of returning 1400 persons to the community from institutions for the mentally retarded.

Generally, there is a common acceptance that institutions are not appropriate places for people to learn and live and that back-up resources in the community must be set up for individuals experiencing behaviour problems. Thus the thrust of the 'normalization' and 'integration' movement has been to maintain the person with a handicap in his own home or community residence, in local schools and in community vocational settings. However, one of the major obstacles to the realization of this goal has been that:

(i) many persons with handicapping conditions had not been provided appropriate learning methods to acquire the skills and behaviours necessary for them to adapt to community living. These skill deficits may be apparent in life skills, work performance, social development, academic skills or leisure activities.

(ii) many other individuals with handicaps have inappropriately learned ways of responding to certain situations. They have acquired behavioural excesses, such as temper tantrums, self-stimulation, aggression, or disruptive-destructive behaviour, which interfere with learning and with their active participation in community living.

As a result we find that normative behaviour is sometimes not developed or excessively developed in persons with handicaps. It is generally these behaviour deficits or excesses, rather than a disability, that result in an individual being excluded from community integration. It is also these behavioural problems which so greatly influence the acceptance of normalization and integration within the community at large.

In 1976 Behaviour Management as a programme was initiated throughout the province, to act as an integral part of all other natural supports in the environment to help persons with handicaps to overcome behaviour deficits and excesses that are handicapping their effective everyday interactions.

Within the community, we have often found that behaviour modification or management is a method that is looked upon with disdain by many individuals dedicated to the advocacy of persons

with handicapping conditions. This apprehension of the behavioural methods stems not from the approach itself but from the manner in which it has been previously applied.

BEHAVIOURAL INTERVENTION

Historical Approach

Historically, behaviour modification was developed in scientific laboratory settings by research psychologists. During the past three decades it has been extensively applied in facilities for persons with developmental handicaps. As a science, behaviour modification methods have been responsible for affecting significant and unprecedented changes in individuals who were previously considered to be incapable of learning. They were able to show that persons with severe handicapping conditions could be taught basic self-care skills, such as feeding, toileting, and dressing, as well as communication, vocational and social skills if appropriate teaching methods were used. In addition, many individuals who were previously aggressive or self-abusive, or spent prolonged periods self-stimulating, were able to be taught more adaptive behaviours which interfere with learning or with the individual's acceptance in the community. Their research has proven that a failure to learn or the presence of maladaptive behaviour is not necessarily a characteristic of persons with retardation, but a lack of effective programming. In fact, many of the breakthroughs made by the early behaviourists, provide the evidence for contemporary advocates to proclaim the benefits of effective programming and the need for developmental supports, which could be available in the

community as opposed to the traditional custodial care in segregated settings.

So why is it that behaviour modification is viewed with such a negative image:

1) First, individuals, especially those with handicaps, who displayed problem behaviour were traditionally considered unsuitable for community living. Modification of their behaviour was accomplished by removing the individual from his home, family, regular routines, and community, to a specialized facility for treatment.

2) Second, since the individual was no longer in a normative environment, the experiences, expectations, and role-models of the environment are institutional in nature. Consequently, the individual is being taught to adapt to a maladaptive environment. Skills and behaviours obtained are therefore functional but to institutional life, not to community living.

3) Third, the treatment approach was often based on stimulus control of artifically induced conditions, better known as operant conditioning. This is learning acquired to specifically controlled conditions, which were situation-specific and not generalizable to the natural environments of the individual.

In addition, these methods have often been considered more manipulative, dehumanizing, and non-normative in nature than what would be readily endorsed or accepted

by community standards.

4) Fourth, within the closed facility, the psychologists were generally able to affect significant changes in behaviour. However, the methods and reasons for the change were unknown to the family and other natural supports, when the individual returned home. The mystique of behavioural change therefore remained with the professionals and further enhanced the myth that persons with handicaps could best be serviced by living in facilities where these professionals were present.

5) Fifth, since the natural environment in which the person had shown these behaviours remained unchanged, and since learning (with persons with handicaps) does not readily generalize from one setting to another, the behaviour changes would not maintain once the individual discontinued specialized training sessions in the specialized wards. Consequently many individuals failed to maintain the change to sufficient degree in the institution to return home or experienced regression if they returned home. Many persons with handicaps ended up being maintained in facilities with their behaviour difficulties still in existence.

Community-Based Approach

The programme that we will be reviewing today is the behaviour management approach that has evolved in our region over the past seven years in order to develop the community as a behavioural support for the persons with handicaps. York Behaviour

Management Services operates as a community psychology department, in a general hospital. The delivery of behavioural management services is provided to the clients and their natural supports on an outreach basis. Treatment services are provided in the client's natural environment by using a mediator model. This means by training, educating and consulting with the individual and the support persons close to the individual in his daily life, including family, social support workers, counsellors and recreation workers, teachers and vocational instructors, and professional support staff. In this model, our service is not a segregated programme, but an integrated approach that is linked with the existing community supports that already exist to assist persons with handicaps to be helped to learn adaptive community behaviours. As you can see this treatment model for behaviour management is significantly different from the previous application of behavioural intervention. The comparison follows:

1) First, the provision of service occurs within the client's normal environment. The individual with behaviour problems is not automatically removed to a segregated experience and excluded from his home, community or regular routines.

2) Second, since the treatment involvement takes place within the normative environment, the changes that are expected for the individual can be more functional to the natural environmental demands and to cultural and social norms that will need to be maintained.

3) Third, the intervention methods are not based on

artificially-controlled environments, but on changing the natural events and consequences of behaviour within the natural environment. Rather than use laboratory manipulated conditions to change behaviour; this model enhances change by teaching awareness of the social learning potential of everyday interactions and experiences. The methods used to change behaviour are therefore based on acceptable community standards of interaction, including normative consequences - a high degree of positive interaction and adherence to consequences that respect client's rights and dignity within society. In addition, the model, adheres strongly to enhancing the strengthening of skills so that the individual is able to reach an optimal developmental potential; rather than just emphasis on the weakening of maladaptive behaviours.

4) Fourth, in the community model, the intervention is accomplished by providing the natural support persons for a client with the understanding and skills to support change in the client in the natural environment. In this model, the key to effective change is to provide service to the critical support persons in the environment, so they can facilitate change. The professionals work to develop competence in persons who support the handicapped person, so that they can develop and support competence within the client. Creating and maintaining behavioural changes is not a brief endeavour but a consistent approach

which is used as an integral part of the individual's life to support appropriate development and to prevent future problems.

5) Fifth, in this model we do not seek to change the individual in an artificial setting and then attempt to generalize this to his real world; rather we focus in on changing the natural environment so that it can promote and maintain appropriate change in the individual through social learning. In this latter case, the environment, not just the person, is seen as a critical element in both the development and prevention of behaviour problems. The person with a handicap is viewed as a component of the environment, not just as an isolated behaviour problem or disability. The effectiveness of change is not seen as inherent of the individual, but of the ability of the environment to support the change. Developing an environment that can maintain the change is a fundamental quality of this model. Intervention involves enhancing the environment to reflect a positive, consistent, functional and disciplined method and meet the individual needs of the individual.

In summary, this model possesses the treatment from the professionals to the hands of the natural supports; from the institutional units to community life; from special treatment sessions to everyday routines and interactions; and from artificially controlled programmes to social learning conditions.

Basic Principles of Service

As you can see Community-based Behaviour Management Services is a treatment model which is not only based on a strong theoretical-scientific basis, but a solidly-based philosophy of education and rights. With the model, we believe we have the tools to make our beliefs a reality for the handicapped persons with whom we work. These beliefs basically are that:

My colleagues will now present some of the components of our model:

Lynann Outram will address the nature of our community-based model to meet the needs of our client population,

Linda Hickey will provide an example of the application of this basic approach to a non-normative multi-bed facility,

and Andrew Harris will describe the extrapolition of this model to maintain a population of clients in our community, who are generally considered inappropriate for community living.

BEHAVIOUR MANAGEMENT SERVICES' ROLE IN MULTI BED FACILITIES AND TRANSITIONAL PLANNING FOR DE-INSTITUTIONALIZATION

A lecture prepared by Linda Hickey for The Association for the Severely Handicapped Conference

San Francisco
November 1983

Within our catchment area there are a number of residential facilities for people with developmental disabilities. Behaviour Management Services has a mandate to provide service to these facilities but more important we feel a moral obligation to assist in creating environments that would enhance the quality of life for the individuals who live there until more appropriate community living arrangements are available.

My role in this presentation is to address first the way we work within the multi-bed settings and follow that with our role in the transitional phases of de-institutionalization.

There is no doubt that the field of behaviour therapy has changed drastically in the last 10 years as have the related fields of education, technology, philosophy and services for people who are disabled, resulting in an ever-widening gap between community based behaviour management services and historically the behaviour modification units.

The concepts of mediator training, functional skill curriculums, age appropriate activities and in fact normalization had not yet reached some of the settings when we began providing service.

A person residing in a multi-bed setting with a long history of

institutional living most likely has learned self-stimulatory and perhaps self-injurious behaviours as adaptive behaviours to fill the time or to compete for attention. We all know too that in these environments there is always the problem of too few staff to care for too many people. Consequently the disruptive and potentially harmful behaviours are attended to - which is why we see these more severe forms of behaviours happening more often in multi-bed settings.

When we became involved with the multi-bed environments we felt very strongly that not only the philosophy, but also the quality of the service provided to the individual did not change because that person lived in a residential environment.

For this reason it became necessary to adamntly advocate that it is not ethical and therefore not acceptable to change a person's behaviour in order to adapt to a maladaptive environment.

It has been in these situations that our focus has become primarily in changing the environment in such ways so that inappropriate behaviours are not longer adaptive.

I would like to clarify as well that the service does not philosophically support the concept of multi-bed living for persons who are handicapped, but given reality that these facilities do exist, we work toward improving the quality in the short term, while administratively moving toward lesser restrictive arrangements.

We have used a dual approach in addressing the design and implementation of staff development programmes and simultaneously through consultation to the supporting instructional programmes

to focus curriculum on functional skill training.

We have learned that these two areas are critical for intervention if we are to affect any long term changes in behaviour.

The decision to become involved in primarily staff management/training programme came after 2 years of many adaptions of mediator training model with limited success. We repeatedly saw staff's own reinforcement and interactional behaviours increase when an individual's specific behaviour change programme was in effect; but were frustrated by no evidence of the mediator's generalization of these to other situations or in fact other residents, and no maintenance of these skills after the client's desired behaviour change had been reached and the specific behaviour intervention programme completed.

At the same time as we were addressing this phenomenon at the programme planning sessions with the team, Behaviour Management Services was asked to design a package for the Ministry of Community and Social Services addressing the Use of Behaviour Management in Nursing Homes in Ontario.

We intentionally designed this paper to focus on the direct care staff - the health care aides and the use of reinforcement in the naturally occurring events of the day. We emphasized the aides potential to play a major role in changing behaviour and preventing severe behaviour problems from occurring.

Another problem needing attention not unique to our settings, was the recognition that the health care aides did not <u>know</u> how to reinforce or interact effectively with the residents of the

nursing home. Knowing what we all do about the effectiveness of lecture formats in learning and generalization we designed a "hands on" staff training programme for a targetted facility which is presently being test run.

The goals of this project are three-fold:

The first to provide front line staff with the ways and means of becoming more effective in their routine interactions with the residents.

Secondly, to train the staff in basic behaviour management, instructional and interactional communication practises, and

Third, to equip the nursing team with the essential tools to independently train new incoming staff.

Given the immediate reality of our situation whatever techniques we taught had to be effective in the environment we are dealing with - specifically times of the day when one health care aide would be responsible for 17 residents.

So, I would like to quickly explain how we do all that!

In each session, the staff follow a process of observing the trainor and recording a specific behaviour - for example the frequency of reinforcement, then modelling the behaviour using self recording while the trainor observes and records, a 5 minute feedback session, and then graphing their data. On non-training days, the staff in training practise and self record and graph the specific techniques of the week.

Using an individual approach in order to work with specific individual's strengths and needs, two members of staff from each shift are involved in the training process at any given time.

The staff work with the trainors in targetting a criteria at each level of training, and when that is met, move to the next stage. The range of skills targetted are: equal attention distribution, delivery of age appropriate reinforcement, activities, materials and interactions, contingent reinforcement, shaping skills and compliance training. The occupa[illegible] therapist, communication consultant and director of nur[illegible] are involved as well in modelling appropriate techniques particular to their field.

A streamlined feedback system is in place as well, for the nurse on duty to reinforce each staff in training for participating in the programme, and the administrator to do the same at regular intervals.

Administratively, policies were adapted to reflect the objectives of the programme, and to include self-recording and reporting data on interactions on a regular basis in the nurses' aides job responsibilities.

Ultimately, staff will be assigned the role of training of new workers as they come, and the programme will become an essential part of nursing homes' orientation package and probationary period. Also, the nurses in charge will be completing regular sweeps of staff's behaviour to ensure reliability in their self-recorded data.

This process when successfully completed will provide a base for the residents to practise, therefore generalize and maintain their new skills and behaviour change.

The second avenue we explore in changing environments is through the functional skill training model that Dorothy, Lynann and Andy have addressed through our participation in case conferences and

individual programme planning we assist in developing comprehensive 24 hour plans. Behaviour management, like physical or medical management must not be implemented on an isolated basis. To be effective the strategies and techniques must be part of the routine of the day.

Some of the most severe behaviour problems referred from the multi-bed setting have been drastically affected through skill building and reinforcement alone. and just as it has taken us two years of trying to develope effective staff training procedures inevitable convincing the instructors in the validity of this positive approach took almost as long.

Another area which we consider to have been extremely fortunate to have been involved in is in the planning of community support services for individuals who are returning to the community from institutional settings.

Using our rescurces and services we will be able to assist in the creation of environments for successful discharge for particular individuals.

By ensuring that individual programme plans are developed prior to discharge through strengths and needs assessments, and the identification of behaviour excesses and deficits, community support services can be developed to meet the specific needs of the individuals they are meant to be serving.

Often we can troubleshoot with behaviour problems of individuals and affect some antecedenal changes prior to discharge to naturally prevent inappropriate behaviours from occurring. An example that comes to mind is a person who while residing in the

multi-bed facility is identified as becoming aggressive around mealtimes, and therefore suitability for community placement was questioned. Using medical investigation available through our hospital, we could identify some metabolic dysfunction and in fact by using a mini-meals system - dividing the 3 man meals up into smaller portions and providing more opportunities to eat alleviated the problem behaviours entirely. This was set up prior to discharge - the community organized to provide this.

It is often the small environmental change that can prevent a serious behaviour problem from occurring.

These type of changes can be achieved through preparing the staff who are managing the community homes even prior to the placement of individuals, if the needs are identified first. As well as teaching the staff specific techniques for specific individuals we can also look at density of reinforcement and make resources available for teaching independent living skills and leisure skills as strategies for changing inappropriate behaviour.

So by focussing on the specific individuals and those areas that have been identified as problematic for them, we can plan services with those factors in mind and ensure a smooth transition and more successful community placement.

The involvement we have had in the planning phases of the closing of the government facility has enabled us to plan our own service as well and apply for expansion to ensure our own resources are adequate and in place prior to the event. This continuum of service supports also enables us to have a variety of intermediate steps able to deal with problem behaviours before a crisis threatening re-admission occurs.

PRESENTATION: Community-Based Behaviour Management

The Association for the Severely Handicapped

San Francisco 1983

Narrative: LYNANN OUTRAM

I will be discussing the different services we offer to the community, specifically what we offer to the people we refer to as mediators: those are any person who works directly on a daily basis with people with developmental handicaps. These mediators include parents, teachers, and other direct-care staff. This is why most of what we do is focussed on working with the mediator to help them learn techniques to change the client's behaviour. Our staff act as consultants only and do not work directly with clients except when modelling is required.

First I will start with a brief history of the development of our different services.

When Behaviour Management Services began seven years ago our major priorities were: (1) mediator training and active programming. I will be defining each of these in detail later on. This was standard procedure for all referrals, cases received.

Initially much of our service was the provision of (2) crisis management. We define a crisis as when a behaviour is in excess eg. aggression is at an extremely high level, eg. 2 major outbursts a day or when a behaviour deficit eg. toileting is so low that the client has experienced a great deal of failure at learning a skill. It was then that a referral was made to Behaviour Management Services. These types of behaviour problems

require:

1) intensive mediator training,

2) intensive and often very intrusive behaviour change programmes.

Therefore, it is much more difficult to change these levels of behaviour both for the mediator, client and consultant requiring both time and energy.

This is why we have changed the focus of our service to the PREVENTION MODEL,(3)prevention of behaviour excesses and deficits before they reach crisis level. We still deal with crisis level behaviours. Andrew will explain more about this but not in the frequency we used to experience.

Developing our service in conjunction with the needs of our community, our mediators, clients, and all other support staff and with our own model of using the most natural and least intrusive method of changing behaviours.

Our service presently has four major objectives (4) to provide:

1) mediator education

2) consultation

3) active programming

4) public education

Mediator Education (5) is a process of disseminating information at the specialized professional level to the people. It is a process by which the consultant works together with the mediator and other support staff involved with the client, eg. physiotherapist, speech and language consultant, family doctor, to learn not only how to change behaviour but more importantly

how to prevent behaviour problems.

The concepts that are discussed include: teaching appropriate communication systems: setting out clear expectations; making sure the client has choices to make; and teaching appropriate curriculum including teaching domestic, leisure, community and vocational skills.

Most of these strategies centre around the concept of changing the environment, changing the antecedents of those events that occur before a given behaviour occurs.

Example: 7 year old in integrated school

Boy engages in head banging each time asked to do his own zipper up in jacket.

1) Approach 1 - Can he do it independently or does he need help.

Change antecedent - Teach him to say or sign "Help"

Can do independently - Adapt zipper - make it easier - use snaps or a pull cord.

Teaching him to say "Help" - best for him.

Ted Carr's latest research is teaching communication skills to persons with self-abusive behaviour often reduces it. Therefore, it concludes it may also prevent it.

We also teach strategies to change the consequences, the events that happen after the behaviour -reinforcement, planned ignoring, etc. However, these techniques are used when behaviour already occurrs and does not prevent it.

Included in the area of mediator training is maintaining and maximizing the concepts of the client's independence(6),rights

and dignity, and age-appropriate and functional skills.

In order for our approach to be effective there must be commitment and co-operation between all those involved with the client and particularily between mediator and consultant.

We train an average of 1300 people each year. There are two aspects to our present training:(7)

1) individual mediator education

2) group mediator education.

When a referral is received by our service it is processed, then assigned to a consultant. The consultant is then responsible for providing each mediator with a comprehensive programme of both the theory and practical applications of behaviour management principles and techniques. I have spoken about some of the principles discussed. Now I will elaborate. We teach a common-sense approach to the management of behaviour.(8) Our most important philosophy is THINK POSITIVE. Most of the techniques we teach, people already know and may use, eg. modelling. Then we teach people how to prompt and shape behaviour, how to reinforce - one of the hardest things to teach is how to consistently reinforce only appropriate behaviour. We teach them to use natural cues and reinforcement whenever possible, and other strategies.

The purpose then is to work with our mediators and develop the skills necessary to prevent behaviour problems (9) but also to:

1) implement a behaviour change programme

2) teach new behaviours

3) teach clients to generalize behaviour change in all

natural environments and

4) ultimately have the client take responsibility for his or her own behaviours.

Due to the differences in our mediator's skills and their ability to implement therse skills, the education programmes are often individually designed. In many cases the consultant provides books, articles, films and tapes from our library to complement verbal information given to the mediator.(10)

We also provide as a guideline only for parents and some professionals (11) a six-week home-based educational package. This package was designed by our Behaviour Management staff and researchers through a grant from the Ontario Association for the Mentally Retarded. It is a systematic training programme which includes discussion on the following topics:

Attitudes and Philosophy towards Parenting

Communicating with Your Child

Teaching New Behaviours

Increasing Desirable Behaviours

Decreasing Undesirable Behaviours

Developing a Behaviour Change Programme for Your Child

The programme provides weekly readings, audio tapes and homework sessions for parents to complement weekly discussions with the consultant.(12)

This all occurs in the mediator's home. The training package provides not only mediator training but also a means of evaluating the readiness of the mediator to begin programming.(13)

This does not mean that each family receives the exact same

training, it is individualized by both the needs of the mediator and the client.

We also provide many sessions each year of group training (14). Group training provides education in the same principles and philosophies as the individual session but allows for the use of films, (16) role playing and most importantly discussion between mediators. (17) However, the sessions are not tailor-made for each individual. (18) To give some examples:

(19) In the past year we have held a variety of group training sessions on the topic of PREVENTION of behaviour problems, have had several guest speakers discussing topics ranging from social skills training to functional curriculum planning as well as others.

During the past year we have begun a group formed for parent education (20) adapting the six-session individual training package for use by a group. A group training session involves 10 to 20 parents (21) who come to 8 group sessions. We also have 2 consultant visits to the home to complement the group sessions and ensure further individualization of the material presented. The group sessions have been changed each time to better suit the needs of each group. Our format is constantly being upgraded. We are finding that many of our parents are preferring to take the group sessions even though it requires more of their time because of the additional input of other parents, and 3 consultants.

We are presently analyzing the statistics from our past 3 group sessions to evaluate their effectiveness. This is based on pre

and post tests given to each set of parents. The parameters being used are:

1) Behaviour Change Checklist

2) Written test on attitudes and knowledge of principles

3) Percentage of change in the behaviour they chose to work on.

For those interested, this study will presented in May 1984 at the Parent Training Conference in London, Ontario.

Because Behaviour Management Services is based on a Mediator Model, mediator training will always be our primary focus. This training is always being updated based on the mediator's needs and current research in the area of behaviour management and education.

In response to the increase in mediator education (22) and the competency of our mediators in understanding and implementation of management techniques, we have developed our consultation services. This is primarily to give our mediators ideas and information on a variety of topics.

We offer (23) two types of consultation, one requires a referral to our services, then is picked up by a consultant who will make several visits to see the mediator and client in their natural environment, home, school, work. The consultant observes, gives feedback in both the form of verbal and written, then will follow up with two more visits, a month apart to assess their implementation. This involvement is usually 3 months and is very flexible.

The other type of consultation (24) does not require a referral. Mediators can come to our office at the hospital by appointment

and have access to a consultant and our library. This service is (25) (26) (27) (28) new and was developed for those mediators who need information and ideas while they are waiting for a referral to be processed and those who do not require consultant observation.

(29) The third service I want to tell you about is active programming. I touched on this at the beginning - now I will go into more detail and give you some examples. This is a service that many of our more complicated and severe problems require. Again, this is our most involved service because it requires the greatest amount of mediator time and commitment but the results are usually very positive when the mediator can put in the time and effort necessary to effect a behaviour change programme. This type of involvement requires first - mediator training which may occur before or concurrently with active programming depending on the severity of the behaviour. This type of programming requires the most interdependence between all persons working with our client. Sometimes a referral will be received to change a behaviour in one environment eg. home. Often it involves changing the behaviour in all environments eg. home and school. Because we require mediator training and participation, it is necessary that whoever are the mediators, agree to do programming, collect and maintain and keep data, etc. We use a 3 month contract to ensure this. At anytime during the 3 months either the mediator or consultant can decide to terminate involvement. (EXPLAIN) This contract is re-negotiated at the end of 3 months if there is a need.

The next few slides are examples of different active programmes we have run.

These are vingettes from start to finish of a toileting programme to increase self-initiations for a 7 year old boy Adam in order for him to attend an integrated class the next year.

(30) Family and consultant - Mediator training includes parents and family support worker.

(31) Mother working on verbal prompts.

(32) Adam before he self-initiated first time.

(33) Adam after he had self-initiated.

(34) Adam receiving reinforcement for his efforts.

(35) This is a 10 year old boy Jason. Behaviour problem: disruptions — kicking, hitting, biting objects. He had engaged in this behaviour for 8 years. When we programme we always choose the least intrusive procedure and always increase a behaviour if we need to decrease another. For Jason we increased his appropriate use of objects and reduced his disruptive behaviour through reinforcement,(36) check marks and favourite activity of periods of time without disruptions. We did this for two weeks - decrease was not substantial - 20 to 17 a day.

(37) Added in a consequence for behaviour, being ignored - practice 3 times using object correctly.

This reduced (38) behaviour within 1 month to 1 incidence a week. After 3 months still at 1 incident per week. His appropriate use of objects much improved. (39) His mother says that there is follow-through at school also.

(40) This is Teresa. She is 19 years old. The behaviour she was referred for was self-abuse - biting, scratching her hand and

head. There were 10 incidents per day. The referral was for both home and school. At home we taught her how to react in other ways to stress situations through cue cards, verbal prompts. Decreased self-abuse taught her to do progressive relaxation once a day. She did not require programme. Decreased self-abuse at home immediately and now one incidence since baseline.

At school on a programme because many more stress situations, she signs a contract each week with teacher and the consultant for time without abuse and appropriate reaction to stress. She does her deep breathing exercises (41) at school when she feels stressed. There has been a significant decrease since programme began.

(42) Here is the actual process we go through each time we receive a referral. Andrew will explain more.

(43) The fourth service we provide is public education. This involves the development of programmes to promote general education to the public of our service (44) and the principles of behviour management.

(45) This often overlaps with our mediator training sessions but by public we refer to our mediators, parents, teachers, etc. who have not had contact with our service and for those people in the community who have limited direct contact with persons with developmental handicaps.

(46) This may take the form of speaking to special interest groups, eg. Local Association for Children with Special Needs, Medical professionals, Dentists, Psychiatrists, Doctors, Nurses,

or by having speakers presenting topics in the field of several behaviour management topics.

These then are currently our four major services.

We evaluate and change our services in response to the needs of the community. This is done through conversing with the (47) people we work with, sending out feedback questionnaires at the end of each involvement. Developing task forces for people working in areas of EDUCATION, VOCATIONAL, EARLY EDUCATION, PARENTS, NURSING HOMES, RESIDENTIAL, that meet four times a year to evaluate our services to them and give us ideas and an Advisory Board made up of members from the community to evaluate the service standards, review and monitor the community-based programme as a whole.

Now Linda will tell you about our role in multi-bed setting and de-institutionalization.

PRESENTATION: The Association for the Severely Handicapped

San Francisco 1983

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In my part of this talk I am going to review what we call the PREVENTATIVE TREATMENT MODEL. This is a comprehensive service model which rather than focussing on a specific problem behaviour tries to look at the whole person and his environment.

At Behaviour Management Services our top priority is to help people retain their rightful place in the community when that place is being threatened by their own behavioural excesses or deficits. Behaviour Management Services uses a positively based skill building approach to reduce possible problem behaviours and teach the skills necessary for the individual to function more independently in his environment.

This is a flow chart of the Preventative Treatment Model which in a very deceptive manner makes everything we do look orderly and logical. It was quite a shock for us all when we discovered our frantic activity could be reduced to this level.

Here at the top of the chart it shows that Behaviour Management Services receives referrals from many individuals and agencies. These referrals are received by our Referral Co-ordinator and then priorized in order of the severity of the behaviour.

During the intake process the referrals are assigned to one of 6 priority levels. The first and most severe is where the individual is presenting a danger to himself or others - such cases are self-injurious behaviour, arson, child molesting,

aggression and severe destruction. The second level is where the client's behaviour threatens him with dislocation from the community. Third, where the client's behaviour is causing serious family disruptions. Fourth, where the behaviour is disturbing the function of his class, home or work. Fifth, the client requires aid with self-help or personal hygiene skills and the sixth level where the client requires training in social skills.

These referral levels are not mutually exclusive and the client may need help on several levels. An example is a recent referral for arson; arson is a top priority behaviour but the accepted treatment for arson is to increase social skills which is priority level six - obviously the top priority applies and a consultant is immediately sent out. In this case we were called a little late - how late? - one cadillac and one $250,000. home - too late! Oh well - I am sure she will learn.

Referrals are assigned to a consultant's case list and if the individual is threatened with displacement a consultant is usually on the scene within 24 hours.

The consultant goes into the client's environment and attempts to prepare an evaluation of the situation. He/she will try to talk with all members of the client's environment and generally try to carry out observations of the client engaging in the behaviour of concern. The consultant then usually conducts library research to find out how this behavioural excess or deficit is usually handled by other professionals. Where warranted the consultant will ask that certain medical or physiological tests take place to rule out possible biological basis of problem behaviour. The

necessity of a medical may seem obvious when considering a toilet training programme but has turned up critical evidence in what seemed like an otherwise straightforward case of head butting. In this ,a twenty two year old woman working in a sheltered workshop - medical investigation uncovered an inner ear blockage which was believed to be causing the client severe discomfort. Once the blockage was treated the behaviour decreased rapidly.

A medication review is also an essential part of our investigation. One of our referrals dealt with a sixteen year old female who was referred for hand biting. A medication review found that her particular combination of medications inhibited saliva production, leaving her mouth uncomfortably dry - chewing on an easily available object - her hand - helped to produce saliva; reducing her discomfort. The behaviour soon dropped out after a medication change.

We have observed in the past where direct care staff in their earnest desire to handle a problem behaviour have violated a person's rights or not treated the client in a dignified manner. An unfortunate example is where three forty year old men had their pockets searched, on pain of losing their job, for the theft of a $12. pay packet. As you can easily imagine the unfortunate handling of this situation might well have caused additional behaviour problems; verbal and physical aggression or destruction for example.

Cases like this have led to our series of preventative workshops on aggression, theft, and non-compliance. These are usually conducted on an in-service basis and are aimed at the successful

prevention and the dignified handling of problem behaviours.

These workshops and other resources for staff are an important part of case preparation in that they provide support and bolster the confidence of direct care givers while hopefully preventing further behaviour problems.

After his/her assessment observations, interviews, medicals, library research, and talking with other professionals, the consultant comes to a critical question....."Do I need additional professional advice?" In some cases due to the experience of the consultant or the relative simplicity of the problem, the answer comes back "NO" and so we exit out the side and skip the next box in the flow chart and go straight to working with the social work support person to set up a case conference. However, sometimes due to the novel nature of the problems or the severity and complexity of the behaviour the consultant does not have sufficient information to deal adequately with the client's needs. At this point the consultant usually discusses the situation with our Director, Dorothy.

At this point a decision is usually made to contact a specialist in this particular area of behaviour. In 1983 alone we have been in touch with Richard Foxx and Judy Favell regarding self-injurious behaviour, Lou Brown regarding curriculum and functional programming matters and Gene Able regarding sexual deviance. These specialists are often brought into direct consultation on this client's problem behaviour.

The next step is usually a Case Conference. This is a conference where all people who maintain important contacts with the client come to share ideas and develop some form of a plan for working

together in the client's best interests. These conferences are important for several reasons - sometimes they uncover differences in the way people are handling behaviour - what is considered serious at school is not a problem at all at home — often just communication between parties - an understanding between home and school, and consistency in handling a behaviour can go a long way to helping the client. This conference activity tries to look at the whole person, not just a specific problem but to consider his individualities and his needs. It is the object of this meeting to set common goals and objectives with the knowledge and consent of all to set the stage so that home and school, work and home can work together. Most importantly, wherever possible the client should take a full part in these discussions and all steps available must be taken to ensure his full knowledge of the objectives and to obtain his informed consent.

After this meeting the consultant attempts to pull the case and his programme together into some form of meaningful whole.

During case consolidation the consultant works to prepare a programme which will teach the client the skills he needs in the most age-appropriate and dignified manner - taking into account the three cardinal rules of behaviour management; fairness to the client, the full rights and difnities of the individual and the principles of normalization. At this point he constantly checks back with the people in the environment - the very people who will act as mediators for the programme.

During this firming up of the case the consultant and the client

may be involved with many community-based resources who can provide treatment facilities. Full use can be made of general hospitals, local psychiatric centres, research centres for disabilities or mental retardation, local dentists, optometrists and professional counsellors. It is important to use community services and not those provided for persons with handicaps. One of the common arguments made in favour of institutionalization or reinstitutionalization is that the person with handicaps will receive better, more accessible and more accepting health services on institutional grounds. Through helping the individual to participate more fully in his community you break down the barriers of his prejudice and show that these reasons for institutionalization are not valid.

The treatment unit that Linda has discussed is to our knowledge the only one which we are aware of which is not facility-based. In our region we have shown that we can depend upon community resources and we do not rely upon institutional facilities.

UPDATE

The one thing which this flow chart does not show is the continuous phone link which joins all the service providers and service receivers.

There are special cases where the client's behaviour puts his place in the community in jeopardy. These are behaviours which might end in criminal charges or with someone being injured.

At Behaviour Management Services we are treating, in community, behaviours which typically are dealt with by sending the person

to an institution. For example — in the past year Behaviour Management Services has accepted six referrals for child molesting, referrals for arson and close to thirty cases of severe aggression and destruction. The tragic irony of institutional placement is that institutions do not treat, they merely incarcerate. At Behaviour Management Services we are aware of no institutional treatment programmes for child molesting, arson or aggression which acept people with developmental disabilities and actively attempt to return them to the community. That is not how institutions work —— they isolate you from children, take away your matches and further restrict your freedom if you hit someone. There is no logic in this - you remove someone from the community because of problems in the community. The institutional environment itself prevents you from presenting the client with the factors which caused his problem behaviour and when you return him to the community he is untreated and the antecedents to his probvlem will again be present - his problem behaviour will quickly return. It is a function of the institutional environment itself which necessitates treatment in the community.

It is our contention at Behaviour Management Services that the only reason that a person should be removed from the community is where that person has <u>knowingly</u> circumvented criminal law and is dealt with under normal criminal law procedures. There is no other acceptable reason for removal from the community.

Dealing with such serious behaviour problems there are cases where moral and ethical issues deserve special scrutiny. Where

there is an additional need to protect the interests of the client, Behaviour Management Services will aid in the formation of a Community Advocacy Committee. This committee is different from the Advisory Board which Lynann told you about, this committee is composed of leading members of the community including a lawyer, a United Church minister, a police inspector, a physician, the director of Family and Children's Services, a representative of the Provincial Government, a consulting psychologist who acts as a peer review for the programming staff, the director of the social work agency and our own Director, Dorothy. To preserve the confidentiality of the client when the facts of the case are presented to the Community Advocacy Committee all names are changed; place names and dates are removed. This group tries to assess the impact of possible risk to the community and to ensure that all treatment decisions are made in light of acceptable community standards and in the best interests of the client. This is a very special group of concerned, unpaid, citizens whose input guards the client's rights and helps to ensure his success in the community by providing feedback as to what would be desirable steps to protect the client's rights and to ensure this person success in the community. Their opinions are consulted during case preparation and once behavioural programming begins.

At this point as active programming begins it is important to check the lines of communication to ensure the agreement of all participants. The first step is generally mediator training. This involves teaching the important individuals in the client's environment certain basic principles and techniques of behaviour

management and trying to ensure their practical application. As Lynann has said, these techniques should allow the mediators to effectively and consistently teach or handle the client's behaviour when active programming begins.

The second stage of active programming is to do baseline observations which will tell us the general frequency or intensity of the behaviour of concern. Often there is a lack of skills and not just a "problem behaviour". While observations would most likely have been ongoing from the case preparation stage these detailed baseline observations will give us a good idea of how much we have to teach, how much we have to increase or decrease the frequency of the behaviour to help the person.

Active programming most often involves four basic processes. First to increase the frequency or amount of desirable behaviour that the client is engaging in. Secondly, to reduce the frequency or amount of undesirable behaviour. The third part is to address skill deficits which may be contributing to the problem behaviour. While aggression may be targetted as the behaviour of concern it may be that the client's inability to participate in a household activity may cause such frustration that he lashes out. An inability to budget money may increase the likelihood that this person will steal. Sticking with our preventative approach by teaching the client a household activity or to budget his money you have provided an alternative response to the problem behaviour often effectively eliminating it and you have increased that person's independence and sense of worth. The fourth step is to teach social skills which will provide a

sound basis for this person to be as effective as he can in his environment by increasing his independence through taking a firmer control over his behaviour and relating to others around him in a more acceptable and autonomous manner.

A well designed behaviour management programme while concerned with controlling problem behaviours must be targetted in the long run to increase the independence, initiative and personal responsibility of the individual. This programming continues until the original problem behaviour is no longer a matter of concern.

At this point the case is down graded to follow-up status where the consultant maintains contact for a minimum of six months and acts to help set up such supports as will best help the individual to maintain an acceptable level of behaviour. The degree of follow-up necessarily depends upon the case and the degree of supports needed. This support can extend from a minimum of six months for a typical motivation or feeding programme to regular follow-up visits every three months for the rest of the client's life for those in our treatment programme for child molesting. It is also important in this stage to provide support and encouragement for the support givers - to strengthen their skills for handling the behaviour.

And once again an overview of the system.

That's the whole thing.

THANK YOU